



ECFS Diagnostic Network Working Group

Coordinator: Nico Derichs, Berlin, Germany

https://www.ecfs.eu/ecfs_dnwg

13th Annual Meeting, London, UK, 11 - 13th February 2016



Organizing Committee:

Jane Davies – Royal Brompton Hospital, London, UK

Nicholas Simmonds - Royal Brompton Hospital, London, UK

Nico Derichs – DNWG Coordinator

Sheila Scheinert – DNWG Assistant

Scientific Program

Thursday 11 February 2016

13.30 Arrive and coffee

14.00 Welcome – Jane Davies (London, UK)

Session 1: When it's not CF: State of the art diagnostics for other chronic suppurative lung diseases

(Chairs: Nick Simmonds, Isabelle Sermet-Gaudelus)

14.05 Advances in imaging of ciliary defects: EM, tomography and immunofluorescence -
Claire Hogg (London, UK)

14.35 An update in PCD genetics - Hannah Mitchison (London, UK)

14.55 Immune testing in bronchiectasis - Austin Worth (London, UK)

15.25 Secondary defects in CFTR in non-CF CSLD: myth or reality? Nasal PD and inflammatory
cytokines in a cohort of patients with PCD - Suzanne Crowley (Oslo, Norway & London, UK)

15.50 Discussion

16.00 - Coffee break -

Session 2: Current practice and challenges of diagnosing CF in ...

(Chairs: Nico Derichs, Jacquélien Noordhoek)

16.30 Norway – Olav Trond Storrøsten (Oslo, Norway)

16.45 Hungary – Reka Bodnár (Budapest, Hungary)

17.00 Greece – Elpis Hatziagorou (Thessaloniki, Greece)

17.15 Tunisia - Samia Hamouda (Tunis, Tunisia)

17.30 How can CF Europe support diagnosing CF in European countries?
(Jacquélien Noordhoek, CF Europe)

Friday 12 February 2016

Session 3: Precisely defining and communicating the diagnosis of CF and associated phenotypes

(Chairs: Kris De Boeck, Carlo Castellani)

9.00 CFF Diagnosis Consensus Statements 2016:

Screened populations - Clement Ren (Indianapolis, USA)

Non-Screened populations - Patrick Sosnay (Baltimore, USA)

9.45 CFTR-related disorder: extended use as label for multiorgan CF-like disease

("CFSPID developing symptoms/CFTR dysfunction/atypical CF") not fulfilling CF diagnostic criteria?

Pro: Kevin Southern (Liverpool, UK), Con: Jürg Barben (St. Gallen, Switzerland)

10.15 Discussion

10.50 - Coffee break -

11.20 Why a diagnosis of CFSPID can be harder to handle than CF and how could we do better?

Jane Davies, Dr Michele Puckey (Consultant Paediatric Psychologist) and CFSPID parents (London, UK)

12.00 CFSPID to CF: The perspective of the adult physician - Nicholas Simmonds (London, UK)

12.30 ECFS Diagnosis Consensus Delphi Process 2016 - Nico Derichs (Berlin, Germany)

13.00 - Lunch break -

Session 4: Diagnostic use of CFTR Biomarker & Genetics

(Chairs: Michael Wilschanski, Inez Bronsveld)

14.00 Real life practice of sweat testing in Europe: Results of the ECFS DNWG survey and next steps –

Natalia Cirilli (Ancona, Italy)

14.30 How to define a CF-typical NPD? Multicenter reference data from the diagnostic ECFS NPD SOP validation study - Isabelle Sermet-Gaudelus (Paris, France)

- 15.00 How to define a CF-typical ICM? Multicenter reference data from the diagnostic ECFS ICM SOP validation study and the ECFS CTN ICM certification process – Sheila Scheinert (Berlin, Germany)
- 15.30 Young Investigator 1: Diagnostic application of ECFS SOPs for NPD and ICM to patients with questionable CF or CFTR-related disorder - Michael Klosinski (Berlin, Germany)
- 15.45 Young Investigator 2: Organoids in a challenging diagnosis of atypical Cystic Fibrosis
Barbara Bosch (Leuven, Belgium)
- 16.00 - Coffee break –
- 16.30 Young Investigator 3: Combining standardized and new CFTR functional tests for diagnosis –
Silvia Vercellone (Verona, Italy)
- 16.45 Young Investigator 4: *Ex vivo* differentiated nasal epithelium as a model for the functional characterisation of splicing mutations in the *CFTR* gene and test of new targeted therapies?
Anne Bergognoux (Montpellier, France)
- 17.00 CFTR3: Collection of clinical phenotype data in subjects with rare *CFTR* mutations –
Elke De Wachter (Brussels, Belgium)
- 17.30 Quantifying CFTR function in intestinal organoids of subjects with rare *CFTR* mutations –
Anabela Ramalho (Leuven, Belgium)
- 18.00 Complete *CFTR* gene mutation analysis in European patients with CF –
Kris De Boeck (Leuven, Belgium)

Saturday 13 February 2016

Session 5: Clinical trials and outcome measures in CF

(Chairs: Kevin Southern, Elke De Wachter)

- 9.00 CFTR gene therapy: what does the future hold? – Uta Griesenbach (London, UK)
- 9.30 Sweat test variability in real life – Francois Vermeulen (Leuven, Belgium)
- 10.00 Lung clearance index: Update on the ECFS CTN Core facility and plans for a multicenter clinimetrics study – Jane Davies (London, UK)
- 10.25 Further understanding differences between SF6 and nitrogen-based MBW techniques – Katie Bayfield (London, UK)
- 10.50 Gastrointestinal outcome measures in CF clinical trials - Michael Wilschanski (Jerusalem, Israel)
- 11.15 - Coffee break –

Session 6: The ECFS Diagnostic Network Working Group - a growing global network

(Chairs: Jane Davies, Sheila Scheinert)

- 11.45 Diagnosing CF in Africa – Refiloe Masekela (Durban, South Africa)
- 12.15 Young Investigator 5: A Molecular Investigation of Cystic Fibrosis in South Africa – Cheryl Steward (Pretoria, South Africa)
- 12.30 Young Investigator 6: Pulsed direct and constant direct currents in the pilocarpine iontophoresis sweat chloride test - Carla Gomez (Campinas, Brazil)
- 12.45 1st Latin American Newborn and Early Screening of CF patients (LANES) Meeting 2015: Summary and DNWG collaboration - Ana Kotnik Pirs (Ljubljana, Slovenia)
- 13.00 Conclusion & DNWG perspectives – Nico Derichs (Berlin, Germany)

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